



Ucare

The Caregiver Guide

Module 14

Caring for the Child with Special Health Care Needs

Leader Guide

UCARE Module 14

Caring for the Child with Special Health Care Needs

PURPOSE

Module 14 will help caregivers of a child or youth with special health care needs to identify supports and resources, interact with professionals, organize records, and plan for future events. Local resources will also be provided to aid the caregiver.

OBJECTIVES

After completing this module participants will be able to:

1. Identify various types of information to collect related to their child with special health care needs.
2. List informal and formal supports, and ways to advocate effectively.
3. Identify techniques for developing parent and professional partnerships.
4. Identify ways to organize financial information and records.
5. Identify key components for planning for the future.

SLIDE 1

UCare: The Caregiver Guide Caring for a Child with Special Health Care Needs

INTRODUCE

Introduce yourself and ask each person in the room to do the same and explain their roles.

NOTE

Introductions are an excellent time to set the tone of the session. Be relaxed and focused. Remember names.

TELL

The handouts are yours to take home. There is room to write on handouts during session.

ASK

What would you like to get out of the session today?

NOTE

Put responses on a white board or a flip chart and during the session refer back to them and put a check by specific topics discussed.

SLIDE 2

After this workshop you will be able to:

- Identify various types of information to collect related to your child with special health care needs
- List informal and formal supports, and ways to use effective advocacy strategies
- Identify techniques for developing parent and professional partnerships
- Identify ways to organize financial information and records
- Identify key components for planning for the future

NOTE

Read the objectives on Slide 2.

TELL

Offer to meet with participants after the workshop to discuss information needs that cannot be covered in this workshop and to discuss where and how to obtain appropriate information.

Any personally identifiable information discussed in the group must be kept confidential. Please try not to use the name of the child/youth that you are a caregiver for.

If you have recently learned that your child has special health care needs this message may be for you. It was written from the personal perspectives of parents who have shared this experience.

SLIDE 3

Parent's Story:

"The day my child was diagnosed as having a disability, I was devastated and so confused that I recall little else about those first days other than the heartbreak."

Another parent described this event as a "black sack" being pulled down over her head, blocking her ability to hear, see, and think in normal ways.

Another parent described the trauma as "having a knife stuck" in her heart.

NOTE

Read the text on Slide 3 out loud to the participants.

TELL

At first you may go through the stages of grief that everyone experiences after a loss. These can include shock, disbelief, anger, blame, guilt, questioning of why it happened to you and your child, and panic or fear that you will not be able to cope.

These feelings can (but not necessarily) come back at different stages through your child's life as new losses happen such as the loss of ability to fully participate in community activities or become independent. So while you can achieve healing, you may feel loss at other times.

Take time to grieve when you need to. You do not have to bear this burden alone; there is much help available to you.

During this workshop we will be talking about information that parents of a child with special health care needs might find useful. A child with special health care needs is basically a child who, because of his or her unique medical or developmental difficulties, has needs in addition to those of his or her peers. You will find that these terms: special health care needs, developmental delay, and disability are often used interchangeably.

TELL

Perhaps these quotes seem a bit dramatic, yet it has been my experience that they may not sufficiently describe the many emotions that flood parents' minds and hearts when they receive any bad news about their child.

Information and planning is essential to regaining control of your life and making informed decisions. The information presented today will give you a place to start.

ASK

Would anyone like to share how you felt when you were told about your child's special needs?

NOTE

Take time to acknowledge each person who wants to share. Ask the parents to limit their comments to 3-4 minutes each.

SLIDE 4

Gathering Information:

- Join a support group
- Read books
- Research disability organizations
- Network with other families

ASK

Have any of you joined a group or read a book that you have found to be helpful?

NOTE

Start the conversation by asking the question stated above. Ensure that the following information about groups and books is covered.

TELL

Joining a Group

Much of the information that will be helpful to you is in the hands, heads, and hearts of other parents like yourselves. For this reason, it is useful to join a parent's group, which can offer you the opportunity to meet and talk with other parents and caregivers who have children with special needs.

Some groups are organized around one particular disability (e.g. Autism, Down Syndrome), while other groups draw together parents who have similar concerns, such as daycare, transportation, stress management, or identifying community programs.

Your doctor, child's teacher, or the Utah Parent's Center may know of groups that meet in your town.

Reading Books

Books written by parents of children with special needs provide information about what they have learned and experienced.

They may provide you with information that will help you identify appropriate supports and services.

SLIDE 5

Information and Programs:

- Seek information
- Find programs for your child
- Community services
- Activities
- Support programs

NOTE

Review the following information and share it with the participants. Encourage their input. Answer questions as they are presented. Ask the participants for any information that they might be aware of.

TELL

Seek information

Don't be afraid to ask questions. Asking questions is one of the first steps in understanding more about your child and the special needs he or she has. Some parents want a lot of information all at once while others find that a little at a time allows them to put things into perspective.

The important thing is that you get accurate information. There is also a list of good parent support websites in your packet. The Internet can connect you with a lot of information. But, be careful about believing all you read. Good and accurate information will be referenced to research or formal studies.

Find programs for your child

Even if you live in the most rural county, assistance is available to help you with whatever information or supports you need. Contact your local school district or health department. Talk with your doctor or church leaders.

Community services

There are programs for children and your family available within your city or town, that include fun activities to get your child involved in the community

Activities:

- 4-H
- Scouting
- Programs at your local recreation center

Support Programs Include:

- Bishop's Storehouse (LDS Church)
- Community health clinic
- Department of Workforce Services (jobs, food stamps, Medicaid, child care, Heat assistance, telephone lifeline assistance)
- Community food pantry

SLIDE 6

Two intervention programs:

- Early intervention services
- Special education and related services

TELL

Two programs for intervention services available under the Individuals with Education Act are:

Early intervention services: These services are designed to address the needs of infants and toddlers with disabilities and their families as early as possible.

Special education and related services: Each eligible child with special needs is guaranteed a free, appropriate public education designed to address his or her unique needs.

Remember: While finding programs for your child with a disability, keep in mind that programs are also available for the rest of your family.

SLIDE 7

Stay Positive:

- Maintain a positive outlook
- Keep the lines of communication open

ASK

What are things that you can do to maintain a positive and open outlook and maintain communication with your partner and family members?

NOTE

Review the following information and share it with the participants. Encourage their input. Answer questions as they are presented. Ask the participants for any information that they might be aware of.

TELL

Maintain a Positive Outlook

Focusing on the positives can help diminish the negatives. For example, your child may have a profound hearing loss, but be a very healthy child. Take time to enjoy your family and the activities you share together. Take each day and problem at a time and keep daily routines as normal as possible.

Keep the Lines of Communication Open

The more you are able to communicate with your spouse, partner or supporting family members during the initial diagnosis and at other difficult times, the greater your combined strength. Remember that each person will approach their role as a parent differently. How you and your partner feel and respond to new challenges may not be the same. Try to explain to each other how you feel, try to understand when you don't see things the same way.

ACTIVITY 1

I'd like you to make a list of activities that you have done with your families or friends that have helped you cope or strengthened your family. For instance: Talking with your family members and making a list of things that you used to do as a family but now have difficulty finding time to do. Now pick one activity that your family enjoys and schedule time with all

family members to go enjoy to make a list of the problems that might prevent you from going and brainstorm about solutions.

SLIDE 8

Emotions and Relationships:

- Don't be afraid to show emotion
- Make time for your own relationships
- Don't forget your other children
- Don't forget to ask for help

ASK

By a raise of hands, who keeps their emotions all bottled up instead of letting them show? Emotions are difficult to regulate.

NOTE

Review the following information and share it with the participants. Encourage their input. Answer questions as they are presented. Ask the participants for any information that they might be aware of.

TELL

Don't Be Afraid To Show Emotion

So many parents, especially dads, hold back their emotions because they believe it may be a sign of weakness to let people know how they are feeling. It is healthy and normal to show emotions. Sometimes professional counseling is warranted, if you feel that this might help you, do not be reluctant to seek help.

In addition to dealing with emotions, having a child with special needs will impact your personal and family relationships if you let it. Here are a few ways to maintain strong relationships.

Make Time for Your own Relationships

This may feel like you're cheating on your responsibilities, but it is important for your mental health and the health of those around you. Share time with your partner. Make a date night once a month. Spend time with other adults (talking and caring for children all day is tiring).

Don't Forget Your Other Children

If there are other children, talk with them, too. Be aware of their needs. If you are not emotionally capable of talking with your children or seeing to their emotional needs at this time, identify others within your family who can talk with them honestly about the things that are concerning them. Some siblings find that having a brother or sister with a disability is a positive experience and they are often more willing to accept people for who they are. Other siblings may feel fear, resentment, jealousy, and neglect. Make opportunities for your child to express how they feel.

Don't forget to ask for help

Everyone needs breaks to rejuvenate and gain new perspectives. Make a list of friends, family, and neighbors who can provide different types of support. For instance, you may have a friend that knows your child well and has offered to watch him or you may have a sister who enjoys shopping and could pick up your list of groceries.

SLIDE 9

Parent and Professional Relationship:

- Work together with the professionals involved with your child
- Learn terminology
- Learn all you can about your child's disability
- Find a good relationship
- Weigh professional recommendations

ACTIVITY 2

Raise your hand if you have a good working relationship with the professionals that work with you and your child. Now keep your hands raised or lower them in response to the next several questions.

- Have the professionals you worked with helped you learn the technical terminology?
- Are you able to have conversations with them- where there is shared respect for each other's point of view?
- Are you encouraged to ask questions without being dismissed?
- Have you ever had the experience of being asked or expected to do more than you could?

ASK

Pick two people with their hands up and ask them to briefly share the aspects of their professional relationship that have made it valuable.

NOTE

Make sure that the following information is shared through this activity.

Work Together with Professionals Involved with your Child

Remember that first and foremost you are the parent of your child. As a parent, you have first hand knowledge of your child's needs, and professionals have a specialized knowledge of your child's needs. The best parent professional relationships are characterized by shared respect, trust, and openness. It is a relationship where both you and the professional exchange information and ideas about the best care, medical intervention, or educational program for your child.

Learn the Terminology

When you are introduced to new terminology, you should not feel embarrassed to ask what it means. Whenever someone uses a word that you don't understand, stop the conversation and ask the person to explain the word. It's important to understand the term well enough so that you are able to provide information to your child's doctor, teacher, or therapist, if needed.

Learn All You Can

Ask questions. Don't be concerned that you are being difficult by asking questions. Write down what you've been told. The important thing is that you request and receive accurate information. A good strategy is to write down your questions before going to appointments or meetings, and to write down further questions as you think of them. Get written copies of all documentation, reports, or professional articles from physicians, teachers, and therapists.

Find a Good Relationship

Find a doctor and other professionals with whom you and your child can work comfortably. Try asking other parents who have children with special needs. They may be able to suggest the name of a doctor, speech pathologist, job coach or dentist.

Weigh Professional Recommendations

Balance recommendations for services, therapy, and other treatments with your daily demands. Don't be intimidated by professionals who expect you to do it all. Be honest with what can realistically be done and what can't.

SLIDE 10

Record Keeping:

Keep Accurate Records

- Health and medical records
- School records
- Financial records

NOTE

You may want to comment that the term “handicapped” is not used anymore and People First Language is important. There is a handout about People First Language which you can share in the supplemented information folder in your toolkit.

ASK

What kinds of documents or records have you found to be helpful to have together in one place?

NOTE

Review the following information and share it with the participants. Encourage their input. Answer questions as they are presented. Ask the participants for any information that they might be aware of.

TELL

Keep Accurate Records

- Information that seems unimportant today may be useful in the future. Your records create a history of development gains or set backs and provide a single source of health and medical records and information that will be needed by teachers, therapists and doctors. Make lists of doctors, notes about appointments, and medicines prescribed, including side affects

Health and medical records

- The Utah Collaborative Medical Home project's website www.medhomeportal.org has extensive forms that will be helpful to maintain your records. A few sample forms and a complete list of forms is provided in the Resources section of the UCare participant booklet.

School records

- As soon as your child begins receiving services either through the Baby Watch Early Intervention Program or the school system, records are critical. Keep notes from meetings with school staff and teachers, professional health care providers, developmental assessments, educational evaluations, and all individualized plans developed for your

child. Remember that assessments and therapy notes from private therapists are also important.

Financial records

- Financial records are critical. As soon as parents find out that their child has a disability, they should begin to organize. Start a program to organize and manage your new financial demands. This not only means managing everyday money, but keeping very careful track of your medical bills and payments. There are a number of money management guides available in most retail stores that explain how to do this.

ASK

Are there other aspects of collecting and keeping information or finding programs that any of you have found to be important?

SLIDE 11

Resources and supports:

- Seek information about financial assistance & service programs
- Use all resources
 - ▶ Division of Services for People with Disabilities (DSPD)
 - ▶ Supplemental Security Income (SSI)
 - ▶ Women, Infants & Children Nutrition Services (WIC)
 - ▶ Medicaid

TELL

Seek Information about Financial Assistance and Service Programs

- Seek information about any and all financial assistance programs. State agencies, like Medicaid, may be able to pay for medical services from the start. Early intervention programs work with children as young as a day old.

Use All Resources

Often, so much attention is focused on getting services for the child that service providers and medical offices may not mention available sources of financial aid.

- You might want to contact the Division of Services for People with Disabilities (DSPD). Your child may be eligible for DSPD services. Children with more extensive needs are prioritized to receive services more quickly.
- Many children with disabilities are eligible to receive Supplemental Security Income (SSI) benefits, based upon their disability.
- Women, Infants & Children Nutrition Services (WIC) provides nutrition education and nutritious foods to help keep pregnant women, new mothers, infants and preschool children healthy and strong. This service will often be able to provide specialized formulas for children with feeding problems.
- Medicaid can make it possible for you to get the care that you need so that your child can get healthy – and stay healthy.

ASK

What other programs have you found locally that have been of help to you and your family?

SLIDE 12

Growing older and more independent:

- Ensure that your child has opportunities
- Teach your child
- Help your child develop self-determination and self-advocacy skills
- Work with schools and other agencies

NOTE

If there are no caregivers with older children, share the following information and encourage the participants to seek additional information as their child grows older.

ASK

How many of you have children 14 years old or older? What are some ways that you have begun to plan for his or her future?

NOTE

Review the following information and share it with the participants. Encourage their input. Answer questions as they are presented. Ask the participants for any information that they might be aware of.

TELL

Ensure that your child has opportunities

Ensure that your child has opportunities to acquire skills now that will make him or her as independent as possible in the future. To live even somewhat independently requires that your child be able to dress, eat, and provide personal care for themselves. Ensure that your child has opportunities to develop

social skills that can be used in a variety of settings (regular classroom settings and exposure to many different environments are useful).

Teach your child

Let them be responsible for their personal needs. This includes experience with:

- Budgeting – opening checking and savings accounts,
- Management of Personal Assistants – recruiting PA's, developing job responsibilities and funding sources,
- Transportation – use of city bus and para-transit services

Help your child develop self-determination and self-advocacy skills

Teach your child to be responsible for his or her own personal needs (e.g., self-care, household chores). Provide opportunities for your child to spend time in community settings. These settings contain many opportunities for choice and decision-making.

Work with schools and other agencies

Work with the school and other agencies to ensure that transition planning for your son or daughter takes place and addresses training for future employment, coordination with adult service providers, investigating postsecondary education or training, and participation in community activities.

SLIDE 13

Planning for the future:

- Plan for when you can't be there
- Explore living options

ASK

How many of you have thought about or started estate planning? Share information with us you've learned as you've started this process.

NOTE

Review the following information and share it with the participants. Encourage their input. Answer questions as they are presented. Ask the participants for any information that they might be aware of.

TELL

Plan for when you are no longer able to care for your child

Seek information from a reputable source to help with estate planning that will provide for your child's care and safeguard his or her eligibility for government benefits.

Explore living options

Explore different possibilities for living arrangements once your son or daughter is grown. Most communities offer services that range from minimum supports and supervision to twenty-four hour on-site supervision to hands-on care. You may want to explore information about accessible housing alternatives and programs for rent subsidy.

SLIDE 14

Organizations and agencies:

- Special Child: For Parents of Children with Disabilities
- NICHCY, National Information Center for Children and Youth with Disabilities
- Utah Parent Center
- Utah Family Voices
- Medical Home

TELL

- There are many organizations and agencies that can help you in a care giving role.
- There is a list of local, state and national agencies in your packet.

REVIEW

Although families face numerous challenges in raising a child with special health care needs, a number of informal and formal supports are available for the child and parents. Developing effective techniques for establishing positive parent and professional partnerships is important as is planning for your child's future. By using the information and strategies that we have discussed today, you can find the support you need to improve the quality of life for you and your child.

SLIDE 15

Take a Break

NOTE

Leader should have chosen one of the ‘Take a Break’ exercises from the Leader’s Toolkit.

TELL

We have one activity remaining. An important part of caregiving that is often forgotten is YOU, the caregiver. You need to take care of yourself.

Ask participants:

- What do you do for you?
- Discuss the answer to this question briefly.

ACTIVITY 5

- Lead the participants in the ‘Take a Break’ exercise you have chosen.
- Impress on the participants that it is important for them to do something for themselves each day. Ensure they understand the “Take a Break” card. Review with them several times and ask questions to ensure understanding.

SUMMARY

Remember that you have courage, strength, compassion, power and wisdom. Thank you for your participation. You’ve been a great audience. Please complete the Feedback Sheet. I welcome your comments and appreciate your interest. I wish you the best in your efforts to care for your family member. If you have additional questions or concerns, I would be happy to talk with you following this presentation.

REFERENCES:

Message from Patricia Smith: Ms. Smith has seven adult children, the youngest of whom has multiple disabilities. She also has a seven year old adopted grandson who has Down syndrome

Behr, J. (1991). [Testimony on early intervention.] In U.S. Senate, Senate report to accompany S. 1106. Washington, DC: GPO.

Callahan, C.R. (1990). *Since Owen: A parent-to-parent guide to care of the disabled child*. Baltimore, MD: John Hopkins University Press.

Dickson, I.R. (1989). The parent-professional partnership: A parent's perspective. In J.M. Levy, P.H. Levy, & B. Nivin (Eds.), *Strengthening families: New directions in providing services to people with developmental disabilities and their families*. New York: Young Adult Institute and Workshop, Inc.

Dickman, I.R. (1993). *One miracle at a time: Getting help for a child with a disability* (rev. ed.). New York: Simon & Schuster. (This book has gone out of print but may be available through your public or university library.)

Mahoney, G., O'Sullivan, P., & Robinson, C. (1992). The family environment of children with disabilities: Diverse but not so different. *Topics in Early Childhood Special Education*, 12(3), 386-402.

National Information Center for Children and Youth with Disabilities (NICHCY) News Digest, "Parenting a Child with Special Needs: A Guide to Reading and Resources," February 1997.

Powell, T., & Gallagher, P.A. (1993). *Brothers and sisters: A special part of exceptional families* (2nd ed). Baltimore, MD: Paul H. Brookes.

Wandry, D., & Repetto, J. (1993, March). *Transition services in the IEP*. NICHCY Transition Summary, 1-28.